Cystic Fibrosis Research News

Title:
Disparities in outcomes by race and ethnicity in the Canadian cystic fibrosis population

Lay Title:
Do clinical outcomes differ between white and non-white Canadians with cystic fibrosis

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What was your research question?
In this study we aimed to compare clinical outcomes between white and non-white people with CF in Canada.

Why is this important?
Cystic Fibrosis (CF) has historically been described as a disease that affects people of European ancestry. That has meant that much of what we know about CF is based on studies conducted in white individuals. This may lead to systematic bias in how non-white people with CF are diagnosed and treated. In the United States, Euro-centric perceptions about CF have led to delayed diagnosis and under-treatment in non-white populations. It remains unclear whether racial and ethnic differences in clinical outcomes for persons with CF are also present in Canada.

What did you do?
Canadian CF Registry data collected between 2000 and 2019 were used. Individual characteristics at diagnosis and clinical outcomes of people with CF identified as white and those identified as non-white were compared. Individual characteristics included biological sex, age at diagnosis, race, and genetic variant. Race refers to a CF clinic-reported race, with categories as follows: Caucasian, Black, Asian, South Asian, Hispanic, First Nation People, Two or more races, Other, and Unknown. Important clinical outcomes included lung function in

terms of forced expiratory volume in 1 second (FEV_1) and body mass index (BMI) as a indication of nutritional status.

What did you find?

At the time of diagnosis, the white and non-white groups were similar with respect to their individual characteristics, and disease severity. The non-white group had similar rates of CF-related complications and bacterial infections compared to the white group, but worse lung function, worse nutritional status, lower treatment rates, and higher rate of hospitalizations. During the study period, the non-white group had a 1.85 times higher risk of death. This corresponded to a 9.3-year survival gap between the two groups: the median age of survival between 2000 and 2019 was 48.8 years in the white group, compared to 39.5 years in the non-white group.

What does this mean and reasons for caution?

Lung Function results are routinely interpreted using race specific equations. This means that lung function for non-white individuals is presumed to be lower than that of white individuals of the same height, age and sex. Using race-neutral equations, (i.e., comparing everyone to the same standard) we found that non-white individuals had lower lung function. This means that interpreting lung function using race-specific equations may be masking how sick non-white people with CF are. This could delay treatments. It is important to note that we were not able to account for socioeconomic status in our study as the Canadian Registry does not capture this information.

What's next?

Differences in survival and overall health outcomes between white and non-white persons with CF may represent systemic biases in how clinical outcomes are interpreted. There is an urgent need to understand why racialized Canadians with CF have worse outcomes, including analysing the potential role of socioeconomic status.

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